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ABSTRACT

Prompted by an awareness of the general public's lack of access to scientific literature in the medical field, this paper documents the practical and ethical desirability of eliminating obstacles to those seeking health information. Discussions based on a survey of the literature focus on (1) the concepts and definitions of information, knowledge, and health; (2) information and health care policies; (3) civic science and cultural science literacy; (4) professional monopoly in health care politics; (5) utilization of health information; (6) health information sources; and (7) the role of libraries in health education. A bibliography is provided. (FM)

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THE PUBLIC'S ACCESS TO HEALTH SCIENCES INFORMATION

by

Theresa Taborsky

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Policy paper submitted to the faculty of the University of Utah
in partial fulfillment of the requirements for the degree of

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Salt Lake City, Utah

April 1980

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INTRODUCTION

Everyone has to deal with human conditions of disease, poor health, mental and physiological ills, chronic ailments or acute medical emergencies, at times on a very personal basis. One's own health problems or those of one's family inevitably bring about the need to seek medical help, to describe and become aware of symptoms as danger signals, to find health care providers, and to select appropriate treatment. In addition to one's personal needs, every citizen wishing to participate in decision making, designing appropriate health care policies for local and national needs, has to understand options, alternatives, economic restrictions, and the potentials and limitations of science and technology. Such decisions must be based on information, on using the accumulated knowledge dealing with health. This knowledge in general is restricted to the professionals, to the medical practitioners acting as the privileged control group.

As a practicing library administrator, active in the academic medical library setting, I am acutely aware of the abundance of scientific literature in the medical field and of its lack of accessibility to most of the potential and ultimate beneficiaries of such information. Medical libraries are well organized to serve professional needs. With the help of federal subsidies, their information resources have become the most comprehensive specialized library system of the nation. Modern technology and information management skills have created a unique knowledge base,

as yet greatly untapped by the general public. The realities of dealing with restrictive policies of "public" libraries and educational institutions, the undemocratic practices of many governmental agencies and private services controlling information have become a concern to me throughout my professional experience as a librarian. My informal but thorough assessment of the librarians' attitudes, through professional contacts, underscored my interest to investigate their justifiability. This questioning became more conscious during my public administration internship in the library setting.

The concern with the information needs of a functioning democracy and the reasons, historical and psychological, for present attitudes, were the object of my literature search, were also the prevalent communication patterns and control of information flow in health care and medicine. Attitudes, philosophical and ethical justifications, were well represented. in the last decade's descriptive and analytical writings which were found pertinent. They explain and give reasons for the existence of professional control over health science information. However, they do not succeed in justifying such attitudes. I believe that the medical library profession, now dedicated almost exclusively to the physician and his subordinate health professionals, can and should address this issue and bring about some liberating change.

The purpose of this paper is to focus on the existing limited health knowledge of the general public and to document the ethical and practical desirability of opening doors to those seeking health information. As methodology, I chose a thorough literature survey, discussing information

as one of the bases for a democratic society, information amounting to control and power. The perspective is that of a librarian struggling under the limitations of a traditional service orientation, accountable only to one established authority group. References to already existing and developing consumer and library trends to broaden the access to medical information were gathered, which suggest the feasibility and timeliness of a less elitist, more consumer-oriented health information service.

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CONCEPTS AND DEFINITIONS

INFORMATION--KNOWLEDGE

Information, in essence, is knowledge. However, it is not knowledge merely deposited and stored somewhere. Information implies usage, accessibility--the process of moving information from one place to another, from the place where it is stored to the individual or the group able to make some use of it--is essential. This process makes possible communication. Thus, reference to information which is effective implies that this information will be publicly available for the benefit of the individual, a group, or society as a whole. This definition of information and its role in our modern society is discussed by Stephen Feinman in a recent paper, emphasizing the usefulness or necessity of information for public life. This creates ethical, moral, or legal obligations for institutions charged with providing such information and access to it.

One must understand that there is a relationship between communication, information, and knowledge. Feinman's definition is:

> Knowledge, for the purpose at hand is simply the apprehension of truth. Information is knowledge which has been captured on some storage media and tends to reduce the level of uncertainty. Communication is the movement of information from one location to another.[1]

These three concepts, forming a continuum, imply the presence of an individual who is seeking knowledge and also a process by which the individual obtains the information.

Webster's offers us this precise definition: Information is the "communication or reception of knowledge or intelligence."[2] The dictionary further defines information as "knowledge communicated by others or obtained from investigation, study, or instruction." It reinforces Feinman's definition by defining intelligence as "the act of understanding" and also "the information communicated."[3] This is knowledge which is vital and is not merely deposited somewhere. Our civilization and our democratic tradition have established public education precisely with this in mind, that an informed citizenry is necessary to maintain "our way of life."

Information scientists agree that the value of information lies in its utilization. Information lying dormant, stored in systems which are not easily accessible, is not fulfilling its purpose. Joseph Becker, in arguing that information is a national resource, declares that "national progress and innovative development cannot occur without the creative and imaginative utilization of accumulated information."[4]

With this same assumption, public libraries have come into existence and have continued in the role of educational institutions making available information to anyone who may need it or want it on any level for any purpose. The library thus does have a traditionally acceptable role as information provider about everything, including health sciences, health care, and health politics.

HEALTH

Health is defined by Webster's as "the condition of an organism or one of its parts in which it performs its vital functions normally or

properly; the state of being sound in body and mind."[5] Synonyms given are "well-being, vitality, prosperity." Thus health information is much more than medical-scientific knowledge. It is any and all information needed for the well-being, vitality, and prosperity of the individual and the society. The World Health Organization, in defining health, includes the concept of information:

> Health is the state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. ...The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health....Informed opinion and active cooperation on the part of the public are of the utmost importance in the improvement of the health of the people.[6]

Thus, WHO, whose aim is to improve the health of the individuals of the entire world, suggests that only the extension of medical knowledge to all peoples and their involvement through informed opinion will bring us closer to this somewhat unrealistic, utopian goal.

HEALTH INFORMATION

In the content of this paper, health information includes but does not limit itself to practical advise applicable to individual health care. Information on this level includes scientific description and etiology of a disease, its symptoms and their interpretation, of predictable progress and outcome, of its statistically "normal" course and the known risk factors. A patient may want to and should be able to know the state of medical technology relevant to the control and cure of his or her condition and about the on-going scientific research which may bring results in the near future. Information about therapies, available surgical and other procedures with all their medical, economic, and psychic implications can help the patient to make decisions, to choose a particular action or none at all. Such health information should be formulated, collected, stored, and recorded in a way to allow access by anyone who is interested.

Beyond the patient's right to know, there is the societal need to have an informed citizenry who can help guide national and local health programs, who can define, support or reject policies, set priorities affecting the health of many and the health of the nation. Health care issues in the political arena, legislation enacted and under consideration on the national and local level, the economics of programs already implemented or planned and the results of existing ones need to be reported to the public in a timely, concise, and objective manner. Efforts of the media to keep the consumer informed as well as reports of administrative agencies about progress. success and failure should also address the need for accountability.

It is not necessary to decide or define for what purposes a particular item of health information was developed and what additional uses it can be put to, even though the creator of such knowledge, the scientists or the data gatherer, may have had only specific, limited applications in mind. It seems that creative use of information depends partly on the individual who gains access to it.

INFORMATION IS POWER

Representative scholars, as well administrators of profit-making information-dissemination organizations, point to the fact that political power is based in substantial part on the control of important information. Richard Diener, in his paper on the evolution of social-political power, equated cultural evolution with the change in the information content of a social unit through time.[7] Perhaps all of us in a democratic society, or any society which sets goals beyond its present status, agree that information and the access to it are a key toward achieving these goals. Socio-political control, that is power, is most

often determined, or at least very heavily affected, by access to strategic information.

The present patterns of access to and control of health information allow for a very narrow power base. It is not now possible to have health decisions made for our entire society or the individual except with the extremely powerful influence of the medical profession, based on its position of privileged information. If it is true that control over information means control over decisions, and thus power over social and economic conditions vital to all of us, then we must be concerned how, in the health care field, the access to information determines the outcome of health care decisions.

Information is a tool, a necessary basis for decision-making, an element of power in the political process affecting health care. There the question is who will establish and execute programs and policies and who will have the information necessary to make decisions which affect all our lives. Our democracy, though imperfect, is based upon the conviction that the consumer-public, the citizenry, should be the ultimate decision-maker for our society. There is hardly any individual not intimately and closely affected by political, scientific, and economic decisions relating to health. Thus it seems almost incongruous that such information is not yet sufficiently available and, in many instances, not even sought after.

It is obvious, even in a democracy, that a powerful, influential part of our society is the small elite of the best informed. Members of this informed elite can often make better, more valid decisions for those

who are less informed than the latter could for themselves. Information is and should be available theoretically to all members of a democratic society, but ultimately only relatively few members of society acquire the necessary information and make use of it. Membership in the "informed society" should not be predetermined by one's professional or political or class status but should be based on self-selection, making the information acquired on one's own initiative useful in one's personal life and influential in shaping the lives of communities and of nations. Amitai Etzioni describes this elite as that which "is a societal control center. It specializes in the cybernetic functions of knowledge processing and decision-making and in issuing control signals for societal units."[8]

When we talk about consumers of health information, we are necessarily discussing a group which is already above average in education and economic status, and is politically active. As many writers have discussed, this elite, which is self-motivated to acquire information, will also use it for power, sometimes to the limited benefits of its own group, yet more often, one hopes, to the benefit of the entire society. These are the men and women who are alert to political ideas and values. They are, of course, alert to ideas and values which will enhance their own lives, state of health, and vitality. Duerr asserts that the average citizen, whom we call health consumer, has very little pertinent information when it comes to substantive political issues which affect him.[9] We should expand the elite group and allow the average citizen more and more chance and incentive to acquire the pertinent information and thus to have an effect on health issues, whether they are political or individual health care problems.

POLICIES

INFORMATION POLICY

Marta Dosa, a professor of information science, discussing information policy, defines it as a plan to develop information resources and their optimal utilization by individuals and institutions.[10] Apparently, most information theoreticians limit their analysis to information which was created for scientists and technicians for research and for technical use. However, in the area of health care, health technology, and health politics, it is not only the scientist who should be involved. Decisions in this area affect almost every member of our society directly, immediately, and very crucially. Thus, the information which is available to the health professionals should be available to everyone who has interest in and inclination to use it, even though not necessarily the technical training needed to create health information.

Dr. Dosa's ideas for a seminar on information policies address this role of information in a total economic and social system, not merely for its scientific and technological applications. Specific health information policy should necessarily address the availability of such information and point toward possible solutions of problems creating barriers to access. These solutions may be national, state, local, or private attempts to organize available material on a scope and level of general access rather than restricting it to specialists.

A paper from the Food and Drug administration says that the purpose of community information services is to help "the citizen to obtain information needed in order to survive and to participate in a constructive way in the life of the community."[11] The scope of information for the public includes, but is not limited to, data on health, education, welfare, employment, recreation, and the structure of the community which relates to these facets. It is suggested there that public agencies or governments are responsible for making such information accessible.

HEALTH CARE POLICY

The issue of health care, its cost to the individual and the public, the government's role in providing and regulating it, and the merits and non-merits of the various health policies as proposed and implemented, have become subjects of public discussion, questioning, and concern at an ever-increasing rate. Some time ago, programs for medical education and research began to proliferate. The wonders of medical technology, promises of miracle cures, wonder drugs, and imminent breakthroughs for solving age-old problems of specific major diseases. have become topics for mass media as well as goals for specific campaigns of consumer or provider groups. Drugs, smoking, drinking, dieting, jogging, benefits and hazards of various lifestyles, the work environment, and industrial and military activities interfering with health are topics of conversation, targets of popular attention. Health concerns are no longer relegated to the doctor's office only or to the privacy of the homes of

the afflicted; they have gone public and become national concerns in the shape of public policies. The public is learning more about health while the government's involvement in promoting and paying for it has increased exponentially.

Government programs are defined and monies allocated to an extent that they influence all medical training, medical research, and provision of health care for special social groups. Specific health problems are being transformed into national priorities. The public is more aware than before, affected sometimes adversely but often helped by public policies on health, and always taxed. But is the public active in selecting the priorities? And, if it is, does it know enough about the issues to discuss them intelligently, effectively?

Herman Somers described the status quo of public health policy:

> Complaints are frequent that the U.S. lacks a national health policy....If by policy one means legislative and governmental administrative actions, it is conspicuous that this nation has been spawning health policies at a proliferating and bewildering rate ever since World War II.[12]

Obviously the fact that the federal government is spending 42% of the total health expenditures of the nation represents an enormous scope of involvement (yet very much short of totally socialized medicine). This percentage represents an increase from a mere 19% in 1935.[13]

Through Medicare and Medicaid, public access to health care has been expanded to include a large segment of the population previously deprived. More than 90% of biomedical research is paid for by the government, and one-third of the construction of facilities. The creation of

new medical schools and other professional educational programs and the rapid increase in enrollment have resulted in a growth of manpower as well as in specialization. Recent legislation has created Regional Medical Programs (RMPs) and Comprehensive Health Planning and has promoted Health Maintenance Organizations (HMOs), all of these aimed to effect better distribution of health care. Some of these programs have been discontinued and/or their effects have proven to be negligible in taking care of the nation's health needs.

The public is aware to some extent that existing policies lack coherence; that programs and plans are conflicting; proposals are controversial; results, if any, are tentative and fragmentary. Yet a single, clear and coherent policy, implemented efficiently and consistently, will not necessarily be desirable and acceptable to the entire public, or more effective in improving the nation's health. Our society should have policies and programs which are based on more informed consent, on needs recognized by the consumers of health care, and not defined solely by the providers of the same. To function effectively, a democratic society does have to live with inconsistencies and compromises, but must be able to recognize the former and formulate the latter with intelligence.

In addition to the basic problems of democratic decision-making, there are the practical problems of inter-governmental relations. Throughout history the states have been the regulators of health care through licensing and standard setting. It is inherent in the character of health service that it is provided on the local level. Examples are the Professional Standards Review Organizations (PSRO) created by Congress and

contested by the American Medical Association (AMA).[14] Similar contests between governmental "interference" and the medical profession suggest that the public, the presumed beneficiary and object of the governmental action, has little if any opportunity to evaluate or influence policy on these issues. It is even to be questioned whether the legislators and bureaucrats, proposing, sponsoring, and implementing public policies, have appropriate data and other facts for analysis. Do they have adequate access to information?

SCIENCE LITERACY

The question arises whether the public possesses sufficient intellectual skills to interpret health related scientific and technical information.

Shen defines science literacy as "an acquaintance with science, technology, and medicine, popularized to various degrees on the part of the general public and special sectors of the public through information in the mass media and education in and out of schools."[15] He further states that "practical science literacy" is the possession of scientific knowledge which can be used to help solve practical problems; thus it is too important to be left to the scientist alone. His advocacy of health science literacy, however, looks at it merely as a tool to achieve better public health, nothing beyond that. Thus he would make science information available on a selective basis to selected groups only. Nevertheless his outline of different categories of "literacy" can be applied to the thesis of this paper.

CIVIC SCIENCE LITERACY

> Civic science literacy is precisely to enable the citizen to become more aware of science-related issues so that he and his representatives would not shy away from bringing their common sense to bear upon such issues and thus participate more fully in the democratic process of an increasingly technological society.[16]

In discussing ways of achieving such a goal, he suggests that the public, in the future, be exposed far more to science than it is today. Teaching of science on all levels of public and higher education should be much better handled.

One could further extend the philosophical discussion why "scientific literacy" is needed to make not only wise but also democratic decisions. It is not the task of this paper to prove whether democracy and wisdom are necessarily complementing each other or are jointly creating conditions to achieve one or the other goal. The thesis here does not concern itself with a dichotomy. It simply suggests that it is up to anyone who has access to information, and thus is in that respect a fully equipped member of our democratic society, to influence political decisions and to pass judgement on what is wise and what is acceptable, what is expedient, necessary, and desirable.

CULTURAL SCIENCE LITERACY

Beyond the concept of practical and civic science literacy is the "cultural science literacy," which is motivated by the desire to know something about science as a major human achievement. It solves no practical problems but it does help bridge the widening gulf between the "two cultures," i.e., the humanities and sciences. Clearly, at present, such cultural science literacy, or the information with which to achieve it, is attainable by very few people. The access is limited not only by the scarcity of pertinent material containing such information but also by the institutions which prepare, disseminate, and guard such material, as well

as by the absence of "basic science literacy," since most of our schools have not provided us with it. Shen soundly asserts that it is "a relatively small audience [but] the contents of cultural science literacy preferentially reached the current and future opinion leaders and decision-makers in many communities."[17]

The problem of the language of science and the difficulty in communicating science to the layman must also be addressed. The fact is that information is only of value if it is or can be communicated to the individual who can make some use of it. Thus communication is an essential factor in disseminating the information to anyone seeking it. Though the individual encounters the difficulty of technical and linguistic limitations in reading scientific or health science information, it seems clear that such difficulty can be overcome and that scientists or some intermediaries can effectively change the language or translate most if not all relevant information for the educated layperson.

Shen has also pointed out that some of the mystique of science is simply tradition; the layman well might realize that the same common sense logic governs all science; as a matter of fact, science tends to be more logical than our everyday thinking, reasoning, and decision-making.[18]

If one of the frequently cited problems in sharing this specialized knowledge with the layman is "scientific illiteracy," it seems purposeless to blame the victim. Nevertheless, the phrase implies that the ordinary person is ignorant by choice. Daniel Greenberg argues:

> It may be time to acknowledge that contemporary science simply defies understanding by all but a comparatively few; furthermore, that the goal of mass understanding is a congenial delusion that

> leaves a lot of people needlessly feeling stupid....This despairing thesis conflicts with the democratic dogma of the importance of an informed citizenry and it invites counterfire about the difference between the understanding science for the purpose of performing research and understanding it sufficiently to be a spectator of its workings and significance.[19]

This dilemma is evident to those who have tried to inform themselves on issues of pure science and technology, without formal and extensive training in these fields, and are unable to come to sufficient understanding by themselves of issues familiar to the initiated only. Seeking a solution for sharing the content and meaning of science, one must turn to the originators of this development. It is the scientist who must accept the heavy burden of translation and interpretation of his work. The job might not be easy, nor very glamorous. Yet it is imperative that such activities be encouraged, funded, promoted, rewarded, and publicized.

A historical survey of the public's understanding of science suggests that the scientist addressing the lay public was commonplace in 18th Century America.[20] It was fashionable to leave one's office or laboratory in order to explain scientific developments to the public. This phenomenon was not necessarily the result of altruism or the desire for democratic involvement. Very often it was a way of obtaining funds for scientific research through lecture fees. Nevertheless, a contact between the scientist and the lay public existed and its appropriateness was not questioned.

Science later became more sophisticated; scientists became a kind of mystical elite. Today it is no longer considered as a proper professional activity for the scientist to popularize his labors. This attitude is very

much reflected in the fact that most research scientists at our universities neither are desiring nor are expected to teach undergraduates. Research and publishing give our faculty more prestige than teaching excellence.

CONTROLS

MEDICAL PROFESSION

Robert R. Alford discusses the professional monopoly in health care politics, stating that the continuous control of the medical profession over the provision of medical services is a basic element of the American health system.

> Physicians have extracted an arbitrary subset from the array of skills and knowledge relevant to the maintenance of health in a population, have successfully defined these as their property to be sold for a price, and have managed to create a legal mechanism which enforces that monopoly and the social beliefs which have mystified the population about the appropriateness and desirability of that monopoly.[21]

This clearly poses an accusation against the medical profession for convincing the health consumer that most of his problems are illness and require professional treatment. This results in visible economic benefits to the medical profession.

Physicians, through their extraordinary access to and use of health information, can and do exert great influence on our concept of health care, on the shaping of policies and programs, and on individual health maintenance decisions. Some writers in this field consider the status quo as proper and acceptable, others question it. There is some evidence of efforts to share this information and thus to share the power with all concerned, but these efforts are barely discernible.

Our laws too define the physician as virtually the only contact which is legitimate and useful within the health care system. Laws

promoting professional self-review of physicians, and the physicians' unavailability to external review or accountability, lend the profession's members a power they exercise freely. The power extends to the control of medical education, thus to the determination of professional standards and the ethical indoctrination of future generations of physicians.

Alford also discusses community participation and politics, noting that public interest groups as well as individuals representing the community are easily controlled, very often by co-opting their efforts and legitimizing them within a particular program, for example, a drug clinic. Such programs then are guided and taken over by the medical profession. They do result not in "equal health" but in splintering citizens efforts to participate intelligently and effectively in health care programs. What frequently happens to health care advocates indicates clearly that one of their major problems is lack of information or lack of sufficient knowledge to effectuate the particular policies they are seeking to promote. Because few members of the community are aware of and knowledgeable about health facilities, and only a few persons need health care at any given time, where many others need food, housing, and schools, advocates are under little public surveillance and their victories have little collective input. They become isolated from the community and, as they are being co-opted by appointments to advisory boards and planning agencies and through other devices, they become advertisements for the "representative character" of their community's governance and they provide further legitimacy for expansion and control by professional monopolies.[22]

Though these statements may seem to be harsh accusations against the medical profession, nevertheless one can accept the fact that political activitists and political groups do lack sufficient information and knowledge, both in the scientific and political field, to become one of the controlling elements in new health care developments; the professional elite remain the sole controlling group.

DOCTOR-PATIENT RELATIONSHIP

According to Waitzkin and Stoeckle:

> the physician's ability to make necessary therapeutic decisions may depend on his power position vis-a-vis that of the patients. The less uncertain the patient becomes about the nature of his illness and the effects of treatment, the less willing he may be to relinquish the decision-making power to the physician. At other times, however, the physician's maintenance of uncertainty may serve no collective function, may merely satisfy the physician's psychological need for power.[23]

Others have also commented on the relationship between power and the manipulation of information. Ignorance on the part of consumers of specialized services helps to preserve the privileged position of the dispenser of the services. The implication here is that the specialist's position may be endangered by the patient becoming his own physician. Information itself yields the power. In the quite different context of information theory, Maslow and Cherry point to the fact that information allows the recipient to select his own future action from a wide range of possible alternatives. Maslow puts the matter succinctly: "What you don't know has power over you, knowing it brings it under your control and makes it subject to your choice. Ignorance makes real choice impossible."[24]

Scores of authors discuss the doctor-patient relationship, their views ranging from the antagonistic to the sympathetic. Ivan Illich, the polemist of many of our social institutions, goes to the extreme of denying the benefits of any organized health care system, especially that of the western industrialized nations. Not suprisingly, his ideas, as expressed in Medical Nemesis,[25] are reviewed, analyzed, and counter-attacked by the medical profession, as well as by those with perhaps more objectivity.

Shenkin's review essay, "Stalking the Irrational in Medical Care," discusses the moral-ethical issues of the doctor-patient relationship.[26] He concedes that humanitarian concerns are often relegated to side issues, as things that would be nice to do after the important problems of medical organization and life-saving have been taken care of. Thus he agrees with Illich that the patient might be "cured" but not "cared" for. Yet medicine can do well with "caring" as it did in the past, before being a scientist became the doctor's dominant personal trait. The reason for this change might be the absence of a mutually participative relationship. It might be that the growing gap between the scientists's knowledge of health and that of the layman increased the physician's desire to be in total control (lack of humility?).

The history of medicine, especially that of western medicine, demonstrates that the policy and politics of health care have always been under the control of the medical profession. As consumers of this health care, the American people are today more and more aware of the problems inherent in such an almost irrationally one-sided control. Contemporary as well as ancient societies have accorded a privileged status to their

healers, based on their belief of equating medicine with superior, even supernatural knowledge or magic. Yet many writers, discussing the physician's role, remind us of the teaching aspect of the medical profession: the word doctor comes from the Latin "docere," which means to teach. Many authors refer to the tendency of physicians to withhold medical information, to restrict it to professional use, and thus to retain the decision-making ability and power over individual patients' and entire communities' health needs.

SELF-CARE

It is one of the "nine assumptions" of western medicine that "health professionals are the best providers for health needs."[27] Another related assumption is that medical problems have medical solution always. One's empirical, personal experience suggests that this assumption is incorrect. Three-fourths of all illnesses occurring in a community are handled by self-medication and most of our diseases are self-limited illnesses without complications. Yet our culture has given the medical profession a virtual monopoly for the provision of health care.[28]

If it is true that the care of the diseased and the solution of personal health problems is more often than not in the hands of the individual or someone close to him, without professional medical knowledge, then it is probably a logical conclusion that knowledge about health problems, personal health care choices, should be made easier to the consumer by providing him with access to appropriate health information. The use of

the word appropriate may be controversial in this context: who is to determine what is appropriate?

We also know that decisions made by the physician for the patient, his advice and orders are often ignored or misinterpreted. Yet even the non-compliant patient, in general, does not seem to question the physician's prerogative to make informed decisions for him.

> The growing expectation that medical science will eliminate disease is unrealistic and should be replaced by preventive and personal health measures. As a profession [this is a doctor writing] we should begin to recognize that the general reduction in morbidity and mortality during the last 200 years are linked primarily to social, political, and economic factors....A medical scientist should participate in societal decisions but cannot claim the outer authority to dominate them.29

It is interesting to note that this author's work has merited the attention of several reviews and commentaries from the medical profession, which is defending itself from the accusation that physicians often behave as though individuals could be treated in a vacuum. Some of the commentaries stress that today's medical school curriculum places heavy emphasis on the study of social and behavioral sciences and on the "humanistic" approach to patient-doctor relationship. Based on individual patients' collective experience in the doctor's office, and in reviewing medical school curricula, this statement seems to be incorrect. Possibly, there is a trend toward some improvement in this respect, but current practices do not contradict the general claim that the medical profession is more interested in treating a disease than a person.

"Very few industries could be named where the consumer is so dependent upon the producer for information concerning the quality of the

product."[30] The consumer's ignorance derives from three causes: The lay person does not know the value of a particular procedure or treatment. He is unable to make informed choices as to where to go for such a treatment and he does not find that the medical profession itself is helpful in sharing appropriate information to facilitate his choices. The confidence gap between producers and consumers of health care leads to unique problems of social unbalance. Is blame justifiably placed on the medical profession, accusing it of maintaining patients' ignorance and uncertainty while those patients prefer to be informed?

Perhaps the major causes of this ignorance are psychological. Visiting a physician on an individual basis is usually connected with illness, unpleasantness, or fear. This may inhibit not only the desire of the patient to know more but, even more so, the physician's desire to communicate bad news or to suggest problems and future suffering. Though this psychological reason is acceptable to a certain extent, one finds that, in order to preserve their power over the patient in the doctor-patient relationship, physicians, using their ability to control the patient's uncertainty, refuse to share information. It is a more charitable but nonetheless inexcusable assumption that the physician simply lacks the time, and often the ability, to convey health information which is appropriate for the individual, as well as comprehensive, comprehensible information which the patient can accept and utilize to benefit his own health.

Most patients feel that they are "supposed" to go to doctors for counselling or reassurance, thus their autonomy for self-care, and the

desire for it is greatly weakened. In advocating more freedom and informed choice Shenkin nevertheless urges that boundaries be defi[illegible] apparently fearing that too much knowledge and consumer choice might endanger some delicate and desirable balance of the patient-doctor relationship. He puts it elegantly and subtly that "our modern problem was to arrange institutions so that citizens can set the goals of the ship of state and technocrats can man the helm."[31]

RIGHT TO HEALTH CARE

Consumerists claim that health care is a right. This concept does imply that one should be able to accept or reject available services. One should have the freedom to exercise choice and, in doing so, one needs appropriate information and access to comparable values of the available choices among health care services. This would apply to treatment, medication, or the total rejection of professional involvement as well as to the options determined by economic and other socio-political limitations.

An entire book is devoted to the refutation of Illich's ideas by an English medical doctor. He points to Illich's accusation which claims that the health care problems on both the clinical and societal level are iatrogenic (induced by the physician). Horrobin's major proposal is to return medical care to the people by removing controls and allowing lay individuals to supply and accept medical care freely. He expands this heresy adding, somewhat surprised, that so little issue has been made of the wealth of doctors. He warns his peers that laymen, in the process of becoming more informed consumer advocates, are becoming aware of the

fact that expenditures for hospital and medical services have outstripped four to six-fold the average increase in expenditures of all other community needs and that some or much of this money has gone to enrich doctors.[32] Accepting this as a fact, one can assume that medical knowledge is desirable as a monopoly as it results in economic gain for the profession.

Illich's main argument is for the recovery of personal autonomy. His very general, humanistic doctrine, more and more embraced by a better educated and informed citizenry, implies the premise that access to health care information, on the personal level as well as in the political context, is not only desirable but also imperative. Only the knowledgeable will be able to exercise their rights to obtain health care and to expand these rights where possible.

One physician's individual view on medical care as a right is cited here to illustrate an extreme negative view; he interprets the right to health concept as immoral:

> Medical care, which includes physician's services [cannot be] considered the right of the patient....The choice of the conditions under which a physician's services are rendered belongs to the physician as a consequence of his right to support his own life.[33]

Here the priorities obviously are not the welfare of the patient, the values are not compassion or even fairness. Such physician-patient relationship would unquestionably exclude any concession to sharing knowledge with the patient.

UTILIZATION OF HEALTH INFORMATION

A 1966 study by Jacob Feldman discusses the dissemination of health information.[34] His comprehensive survey addresses health information in particular in order to interpret its utilization and its effects. Though somewhat dated, the findings may be valid still as descriptions of those in the population who seek, find, and use health information, and as an analysis of whether it has an effect on society's general health. He does not conclude from his survey that disseminating information, making it available on an "on demand" basis, is desirable. Feldman emphasizes that many other factors, besides the availability and content of the information, influence the actual behavior of the patient or the decision-maker. One's basic beliefs and moral attitudes also help determine how one receives and uses such information. Feldman's survey was able to test the retention or awareness of available information among certain groups: For example, middle class women have more comprehensive and specific knowledge of certain health care issues, such as cancer symptoms, and the treatments available.

Basically, these findings support the view that only elite groups have enough interest to make an effort to acquire health information. Some correlation exists between the educational level and the retention of such information. Apparently, no or almost no significant correlation exists between an individual's behavior and the absence or presence of pertinent information. This study confirms the assumption that those of

higher educational achievement will seek and find additional information in the health areas as well as in other areas of knowledge. Thus seeking information correlates with one's original educational level. Motivation is the additional crucial factor in utilizing information.

The level of information assimilated does not necessarily correspond to the needs of the individual. E.g., the aging or the chronically ill do not necessarily know or wish to know more about their own disease than those who always have conducted their affairs by using and seeking information as an essential element in their personal decision-making process. This leads us back to the original premise that educational attainment, knowledge, and thus power and socio-economic status go hand-in-hand. It does not lead to a clear-cut separation of cause and effect. Feldman states it thus:

> Occupation and income are also very highly correlated with education and with each other, which makes the isolation of their separate effects problematic at best....A person whose contacts are chiefly with persons of high socio-economic status is expected to keep reasonably well informed about matters of current interest, ranging from news and cultural events to the latest ideas about homemaking and child-rearing to lay medical knowledge. Such people not only acquire information for its utilitarian value, they also acquire it...because they are both expected to be and expect themselves to be knowledgeable...What is startling is the fact that personal relevance of the information plays as small a role as it does. While the individual's perception of his health status strongly determines his use of physicians' services, it has little to do with his acquiring health information....Apparently general intellectual curiosity and capacity to learn play a much greater role in obtaining health information than do the person's health situation and his feelings about it.[35]

Thus we seem to have at least one segment of the population well disposed, even eager to assimilate information. Barriers, which have been erected by the medical profession in relatively recent times, to regulate

or limit access to medical knowledge, may be crumbling. Elitist trends, supported by the exclusively scientific and technical education of the medical doctor, also helped separate him from his patient. Yet the humanistic attitude, the service orientation to help the person, not merely to treat an illness, the old family doctor's communication skills may slowly come back.

HEALTH EDUCATION

GOALS AND DEFINITIONS

Health information, to serve the non-specific goals of science literacy, is rarely mentioned even in government proposals, though the literature abounds in discussions of the need for information as an educational tool. Health education is being provided by numerous health agencies. The information provided by health education programs tends to be very specific, its scope limited by the provider with specific goals for selected target groups, like cancer patients, alcoholics, occupations with high potential for health hazards. They are often determined by special needs of local communities or of groups with certain characteristics.

Webster's defines education as "the act or process of providing with knowledge, skill, competence...desirable qualities of behavior or character or of being so provided especially by a formal course of study, instruction, or training."[36] Thus the main aspect of education is emphasized: its goal is a certain type of desirable behavior or character. It is the educator who will decide what is desirable and which character we are aiming at. In health education, the maintenance or regaining of one's health are the obvious goals. In current programs, specific professional groups, often with vested interests, are the ones who determine what health education should have for its content, what its scope and

depth should be and whom it should address. Health education is a very much-promoted branch of health maintenance programs. But the range of health information should not be limited to educational programs for special groups only and it should not be aimed only at behavior modifications, which is the principal goal of educators. It should also enable the informed public to apply such knowledge for personal and political health decisions and goal setting.

Abundant literature exists on current activities concerning health education. There are historical reviews, proposals based on ethical or legal considerations, discussions of the political aspects of consumer needs and ultimately and predominately the need of patients to be educated on particular individual health problems. This literature for health education in general does not clearly separate the two concepts of providing health education and health information. Some definitions for health education suggest a relationship, agreeing that health education goes beyond the process of providing information to an individual or to a target group.

Behavior modification as a goal is stated, or at least implied, in most discussions concerning the need for health education. In the global context, turning to the World Health Organizations's definition, we become aware of the differing perspectives on and differing needs for health education in different societies. The major efforts by and results from WHO's programs are within the health education context. This organization, as probably all public health efforts, considers health education as one of the major tools toward achieving higher standards of health. This fact

is exemplified by the well-known and popularized comparisons of health care methods in countries other than ours. We know about the barefoot doctors in China, about public health programs in underdeveloped countries, about specific goals to be achieved through education methods--whether it is birth control or eradication of specific epidemic diseases (typical of tropical countries).

Health education has been happening everywhere and it is still a major issue in improving the health of entire nations and societies. Health education is often part of public school programs, part of governmental efforts. It brings para-professionals to teach the ignorant about basic personal care and hygiene. In the United States, because of our advanced technology and educational level, these goals and programs no longer have the practical usefulness of the past. Past methods, their validity, and the history of previous successes have been forgotten.

Ann and Herman Somers, the contemporary leading proponents of consumer health education, discuss in their volume on health and health care the by now well-known dichotomy or dilemma which developed in our medical system: Medical treatment has become synonymous with cure.[37] Medical and health services are to guarantee health itself, no longer including the element of health education (until recently). Today, again we are told that the patient must become a member of the health care team. This he can only do, both on a life-long basis and in specific crisis situations, if he receives the necessary health education. Health education in this context, is not the education of a professional who will provide help but that of all citizens whose educational sources are the schools as well as the media. It is specific information as needed for special problems.

PREVENTIVE MEDICINE--PUBLIC HEALTH

A very visible trend in preventive medicine is to reach the health consumer with specific information regarding health problems. "Health education," looked upon as an essential and fundamental part of preventive medicine, has become a top priority in various government programs as well as of private philanthropic or consumer oriented organizations. This may be the field where scientific knowledge is translated into understandable formulas, directly applicable to certain specific conditions, individual or social ills. The public, as well as some of the medical profession, seem to agree that today's health problems are not merely physiological malfunctions; behavioral and social elements are both the cause and the remedy for these. Lifestyles have to be altered and environments changed, collectively and individually, and therefore awareness, knowledge, and information are the key to improved health for our age.[38] The assumption that awareness is the first step toward behavioral modification to achieve specific health goals is the justification and incentive for health education programs.

In looking at our health education programs from the public view, Horace G. Ogden[39] refers to the roots of health education as entwined with the history of public health. Twenty-five years ago, the main goals were to eradicate certain categories of diseases and it was assumed that, by removing ignorance, health education would evoke desired actions. Thus, information was regarded as the most important variable in improving public health. This attitude probably developed because the public health

programs were governmental. Public action could affect changes in society's health without directly involving its individual members in the choice of appropriate action. The epidemics of contagious diseases have been eradicated or alleviated by public immunization programs, improved water supply, better working conditions, communicable disease control, and inspection of food and drugs.

With raised standards and general availability of a healthful environment, more subtle problems to be dealt with now need the understanding and participation of individuals. Today, apparently even the basic hygiene and self-care education, formerly incorporated in the public school programs or handed down within the family or by the family doctor, through the women concerned with the welfare of their children and other family members, is no longer typical. As medicine has become more specialized and health care more professionalized, the generally shared knowledge of health principles is no longer available or is perhaps not even considered to be needed.

HEALTH EDUCATION IN SCHOOLS

Nicholas Galli discusses the foundations of health education in the context of the educational responsibilities of our public school system.[40] His views are valid and interesting but again limited to those of the professional educators wishing to affect patterns of behavior toward healthfulness. It would be interesting to discuss what Mr. Galli means by "healthful" and whether this term necessarily has an absolute meaning

to all concerned. It is quite possible that healthful behavior is a matter of interpretation, culture, personal priorities. Thus someone with a chronic disability or disease may consider his handicaps as healthful or acceptable behavior within his own limitations. Drug addiction or the other side effects of certain life-styles may be viewed as the trade-off for individuals preferring their own sub-cultures with values, including those for health, differing slightly or entirely from priorities of the general public. Therefore, a general policy setting in health information or education may not be acceptable in a society so multi-faceted and non-homogeneous as ours.

Galli's article informs us, perhaps predictably, that public health education was one of the prime objectives of every policy-making group in American education. As far back as Benjamin Franklin's time or that of the first Commissioner of Education in the United States, we find references to the desire to develop health education within the school system. In the 1938 policy statement of the Commission on the Reorganization of Secondary Education, we find the same idea of educational goals expressed:

> The secondary schools should provide health instruction, inculcate health habits, organize an effective program of physical activity, regard health needs in planning work and play, and cooperate with home and community in safe-guarding and promoting health interests.[41]

It further states that the content of health instruction belongs in the (public school) curriculum because such knowledge is necessary and is most efficiently learned in the school and no other public agency provides such instruction.

Will the schools thus guarantee health as an outcome of education? Health education on this level seems to be a necessary though only minimal foundation for the future health information needs of every citizen according to his own perspective and that of society. Health education becomes a continuing individual process, possibly quite analogous to the trend in all education, personal or professional, where formal schools no longer provide more than the basis for developing attitudes and skills to find further information, geared to particular, individual, changing future needs. The health education which our society and our government are talking about is the essential foundation but certainly not the total solution to our health information needs.

THE GOVERNMENT'S ROLE

According to the Somers:

> Given the inability of most doctors to find time to deal with such problems, the lack of health information and the insufficient and ineffective effort of health education, we cannot quite believe that, if all schools of the health professions and all hospitals could be required to allocate a certain percentage of their budget and efforts in our health education, this would result in better health care.[42]

Is it really true, then as the Somers claim, that the individual with the greatest potential as health educator is a doctor? He does see the patient when he is most receptive to health councel, when the patient is really motivated by his distress to seek the knowledge which will help him solve his problem. Yet, most doctors are too busy to take on this extra burden. Many lack the inclination and probably the know-how to share their specific professional knowledge.

Somers' idea of patient education in hospitals is probably more effective than the often feeble efforts of individual doctors, but it is limited to a particular patient's temporary needs in one specific situation. Their solution for a source of comprehensive and general health education is the recommendation for a "National Council on Health Education."[43] This is an uncomfortable idea, leaving such intimate issues as personal health care to an impersonal bureaucracy. This council would be responsible for national policy and thus take the initiative and the decision-making as to the level and content of health information basically out of the hands of the citizen. This council then would recommend and monitor national policy in such areas as teacher training for formal health education courses, curricula for grade schools and colleges, programs for adult education, programs for the mass media, health education in hospitals and other public and publicly supported institutions, and third-party reimbursement and consumer participation in the health care programs utilizing health education techniques.

The central focus of health education is to effect healthful patterns of behavior. The implication is that health education, if it becomes a national policy issue rather than being left merely to individual choice, will remain in the hands of particular interest groups, namely that of the medical profession. Perhaps other professional groups or certain consumer interest groups combatting their particular problem, for example cancer, will also strongly influence the availability and scope of health education.

EFFECTIVENESS OF HEALTH EDUCATION

We are also aware of the fact that our health status has remained static for many years, after having achieved unique advances during earlier decades. Health education is again a public policy issue as well as the concern of individuals, the general consumer and, of course, the patient with specific problems.

One of the writers from England[44] suggests that this idea is neither new nor obsolete. From time immemorial, there has been some form of health education which provided information and knowledge in oral or written form. Many societies, clans, classes, or families had or have a built-in formal or informal system of transmitting empirical knowledge about health. He quotes the World Health Organization:

> Health education concerns all those experiences of an individual group or community that influence beliefs, attitudes, and behavior with respect to health as well as processes and efforts producing change when this is necessary for optimal health.[45]

This interpretation of health education implies, as already mentioned, a change of attitude and behavioral modification which, according to many educators is the only valid aim of education. Thus it is more than the mere imparting of information. It should be viewed from the perspective of its effectiveness by measuring its results.

The idea is repeated in current literature that acquiring knowledge about health does not necessarily or measurably result in proposed change of behavior. This is made clear in the discussion of many specific health education programs targeted to help solve particular problems of individuals or of society; e.g., information disseminated with regard to

alcoholism, drug addiction, nutrition, and the management of self-care in particular disease situations.

It seems that our society today has less need than formerly of public health efforts to combat specific unhealthy conditions like contaminated water, spread of epidemics, and contagious diseases. Health care methods have changed to a one-to-one relationship between patient and doctor and their effectiveness and the amount of information shared with the public depend very much on the attitude or interest or ability of that particular doctor in specific problem situations.

The most visible and possibly the most effective programs are those reaching and educating individual patients who are to use their intelligence for self-care (or care of family members) to get well or to monitor a chronic illness. Patient education is a growing concern of the health professionals, mostly reaching hospitalized patients or those under continuous care. Patient education is only one aspect of communicating health information to the consumer, though it may be the one where visible and tangible results are sought after.

Yet surveys and literature on patient education do not necessarily or conclusively demonstrate their effectiveness. One indirect, though essential, benefit of interest to the general public should be the economic one. There again, actual results have not been demonstrated. Figures measuring the number of patients reached, the scope and length of program planned, the quantity of hospitals and health educators involved do not, perhaps cannot, answer the ultimate question: has the patient's health actually improved or have health hazards been averted or diminished

because of the information contained and transmitted through these education programs? Or is it even valid to want to find measurable, specific results of health education programs?

Werlin's study concludes with specific recommendations to help evaluate health education programs and determine measurable results. The question remains unanswered whether improved health standards, desirable changes in behavior, favorable change in morbidity or mortality are attributable to information disseminated in educational campaigns.[46] Health education is obviously not synonymous with prevention. Yet it is the most visible information to the public, supported by legislation like PL 94-317: The Consumer Health Information and Health Promotion Act, 1976 funded by federal, state, and local governments and by innumerable private agencies. The fact is that no direct causality could be demonstrated between anti-smoking campaigns and variations in lung cancer rates between patient education efforts and faster recuperation, or better management of long-term illness by the patient.

Walter McNerney asserts that, beyond the goals set by bureaucracies and institutions,

> we are dealing with a felt need by individuals to shape the course of their own destiny through broader participation in institutional decisions and a growing realization that the individual must participate in his own salvation as an individual. In effect, the new emphasis in health education is a part of a cultural adaptation.... The total impact of medical and health services is the visible tip; the way people behave is the iceberg:... it [is the result of a complex of hereditary, economic, social, and cultural forces.[47]

The warning here is that the public reached by these professional educational efforts is only 10% of the total population, those who experience

pain and discomfort to the degree that they need the administration of physicians, hospitals, or other organized health care facilities.

The quality and content of health education is not discussed by McNerney. Obviously, the scope is limited to what the health care provider deems appropriate to meet individual needs only. Recommendations to improve, stimulate, coordinate, and evaluate health education programs do not seem to go beyond the constraints of dealing with specific "target" groups. McNerney's address is suggesting merely more centralized efforts (regional clearing houses) and resource materials useful to and prepared for the health educator. Communication and information networks are proposed--these are all programs to be under the direct guidance of the medical profession. His argument goes that it is "credibility which makes information useful, which gains enormously when the information relates to the person's own health and comes from his or her own physician."[48] Yet the same author (president of the Blue Cross Association) admits that, "some doctors do not want their patients to get their information from any source except themselves and more often than not these are the same doctors who tell their patients little or nothing and evade questions whenever they can."[49]

Though this general condition can be improved and may already be changing, the opinions of observers of the health education field range from a negative, perhaps unhealthy, skepticism that there is nothing to be achieved by improved communication toward the goal of improved health to the other extreme of overzealous advocates and "practicioners" of health

education who wish to achieve visible, measurable behavior changes and thus obtain an optimum of health care and perfect health standards. Hardly any of the authors of the literature reviewed were suggesting that the "consumer" should have greater, total, choice by being made aware of all health information which is available.

HEALTH INFORMATION SOURCES

To some extent, the needs of the public for more and better information are recognized: the mass media, popular magazines and other publications, news reports, and even entertainment contain more and more medical stories or discussions of social problems related to health. In examining these media programs for their content and for the completeness and correctness of their scientific-factual message, one can recognize their tremendous limitations in trying to communicate complex, difficult matters briefly and entertainingly. According to some critics, such information is 70% incorrect, misleading, or even untrue.[50] Yet there is hardly any other easily available, readable, and yet reliable literature written by experts for the benefit of the public.

There are other, similar views expressed, at times not without the known bias of the medical profession, jealously guarding the prerogative of interpreting medical knowledge: "...There are treatises that are written for the health professional. They are not meant for the layman to read or interpret. There is material that is written for the layman including controversial works needing a professional to interpret it."[51] The concern about the layman's ability to understand information hitherto privy to physicians only is dismissed finally, suggesting that the doctor has neither the time nor the obligation, perhaps not even the ability, to explain. Acknowledging the increasing demand for medical information and the growing educational level of the population, the suggestion seems to

be that "health information providers," an already emerging breed, should be the guardians and processors yet not the interpreters of such information.

MASS MEDIA

Our main choices, nevertheless, still seem to be the heavily popularized, simplistic, sensationalized, and through commercial interests often biased, mass media sources or the primary source literature written by and for experts, inaccessible as to its content or its physical and organizational location. The general public does get information from the mass media. Though their quantity is abundant, their scope and quality leave much to be desired. They seem to be useful in focusing at contemporary issues and presenting health topics deserving public awareness and political action. These are more often than not the topics transformable into entertainment or selected for their commercial usefulness. Ratings, sponsors, newsworthiness or sensationalism determine the scope of attempts even at factual reporting.

Though it is easy to curse the darkness, it might be better to light some candles by improving the quality, range, and reliability of mass information. A study which measured the scope of unreliability of health information on commercial television did recommend, years ago, the use of health professionals and their educational skills so that the potential of the media should not be wasted and abused.[52] Perhaps this recommendation has not gone completely unheeded. Lacking more recent surveys, we may nevertheless notice that some progress has been made in this regard. Beyond the scope of Dr. Welby and the medical advice columns

of family magazines, new features reporting on medical breakthroughs, investigations, and consumer group activities reach the masses with immediate and general appeal. Scientific documentaries and programs of specific social significance are becoming part of the less commercialized Public Broadcasting System.

If we are concerned with the numbers having access to the mass media, it is inevitable to conclude that their potential power and impact is enormous. Barnum (in 1975) estimates that 230,000 doctors are reading the Journal of the American Medical Association, whereas Readers Digest has almost fifty million readers. Beyond that, television viewers are a daily audience of over a hundred million.[53] Television is effective in impacting dramatic facts upon the masses. Its power to capture the listener and add visual reinforcement to its messages and its accessibility to all levels of audiences could be used to reach those who need to be made aware of health information as a helpful tool in solving personal and societal health problems, information which may be featured in the disguise of entertainment or reporting.

SCIENCE LITERATURE

Lancaster and Smith, in writing for librarians, state:

> Science communication is no longer concerned exclusively with transfer of information from scientist to scientist. The transfer of results of scientific research to the practitioner is assuming greater significance. So is the matter of "vulgarization"--informing the "man in the street" of science progress and accounting for that part of the tax dollar which is consumed by scientific research ...these are very special communication problems requiring "repackaging" of research results, translation from scientific to more

> popular terminology. Special purpose journals, alternative communications media, and various types of "extension agents" to carry the benefits of science into the fields, the factories, the hospitals, and other application environment.[54]

The authors, being librarians, are keenly aware of the need and perhaps the lack of concerted effort to communicate this kind of knowledge to the average reader. They do not offer a solution, a way, a specific method to achieve this bridge between the creation of health science information and the consumers of such information. They do suggest that libraries and librarians are one of the "extension agents."

There must be some who are willing and able to speak for science, even with eloquence, style, and sometimes drama, yet in layman's terms, in order to keep the vital segment of contemporary medical science accessible to the consumers, beneficiaries, and policymakers. That this consumer need is there and growing is documented by a sample survey of news coverage back in 1965. Medicine and public health topics placed second among all science issues (that year, satellites and space predominated).[55] This survey measured the retention of some simple typical scientific information available then in the media, without concern as to their long-range effect on the science news "consumer." (One interesting finding, though perhaps irrelevant to the issue of availability of health information, was that men tended toward science items, women toward medical news. Does this perchance suggest that the average person, if as a woman less thoroughly educated in technical and scientific matters, can nevertheless absorb and appreciate medical topics?)

The profile of the science and medical news consumer emerged to be the better educated, with higher incomes, and consistent in their search

for solid information through the media. Further speculations point to some factors: Some study of science through formal education lends the foundation for "science literacy"; it may provide a bridge for relating scientific (i.e. medical) developments to public affairs.[56] There seems to be the suggestion that science courses stimulate a life-long interest to read more about science. It is then appropriate to applaud the increasing emphasis on science education on the public school level. It may be even appropriate to assume that the scientific- technical character of the literature of health no longer is or needs to be a deterrent for comprehension by the general public, or at least for some of its intellectually more curious and socially more conscious elements.

LIBRARIES

THEIR ROLE AND THEIR USERS

The premise that information is a national resource and its maximum availability is in the national interest is the foundation of American librarianship. The National Program for Library Information Service states, among other things, that all people have the right according to their individual needs to realistic and convenient access to this national resource. The discussion of the social use of information agrees with the concept that information, power, and wealth are inextricably linked.[57] This interdependence of knowledge and power is especially exemplified in the field of medicine and health care. The possessors of information are not too kindly disposed toward the idea of letting the public freely browse in their libraries. They even claim that such access to information is not in the public interest. This claim usually justifies attempts of censorship to maintain political and moral "purity and homogeneity." Often people are required to prove the need to know and to pay for the information. Thus, both politically and economically our present information access is limited, in spite of the fact that laws and regulations have been created which make it possible for us, though not necessarily very easy, to find information at any level. Intrinsic limitations exist in available databases and in public and other libraries' ability to make information available.

A recent (1979) invitational institute for hospital librarians addressed the issue of the library's role in the context of patient health education.[58] Discussions at this gathering attest to the growing, but still minimal role the libraries play in making health information available. The right of the patient to informed consent, to self-care, to environmental safeguards, was prevalent as the dominant theme of the discussion. The hospital library is acknowledged to have a supportive role, supportive mostly towards the hospital staff's information needs as educators, thus only indirectly providing patient information, preselected and recommended or eliminated according to existing policies or decisions made by the provider of health care. Thus information is to serve specific health care needs only.

The typical users of libraries are the segment of the general public who wish to go beyond the mass media, to enlarge their intellectual horizon, not only when information is thrust upon them, but through actively searching for it. This quest for understanding, often but not always coupled with the desire to use the acquired knowledge in problem solving, has traditionally been seen as justification for the support of library service. Library information should be and usually is freely available, unprogrammed, uncensored. Its range, scope and level are limited perhaps by economic restrictions and human limitations; nevertheless, it is not likely to be manipulated by special interest groups or aimed at the interests and needs of a few, privileged or underprivileged users only.

The literature found in libraries is collected usually with more focus on permanence than on current and popular or sensational

appeal. Thus it necessarily complements and expands on the information and health news offered in the media which tend to seek controversial or political appeal rather than solid informational value and scientific reliability. In a library collection, political issues or moral and ethical perspectives can be illuminated from more than one side. Commercial interests in selecting library material are usually negligible. Yet are the libraries with such potentially solid usefulness really filling the needs discussed?

LEGAL PROBLEMS

It is interesting to note that many over-concerned librarians lend considerable attention to the real and imaginary legal restrictions on providing medical information in a library. No librarian has been sued yet because of the information provided. The distinction between information and advice may become an issue of litigation some day if the librarian's role can be construed as practicing medicine without a license. However, even the most conscientious librarian must function under the premise that adult library users can, should, and will decide for themselves how they will apply the knowledge they acquired anywhere, including in a library.

An author with a degree in medicine as well as in law addresses these ethical and legal problems. He counsels the timid librarian thus:

> If you provide information and information only--not opinion, not diagnosis, not treatment--you will never be accused of practicing medicine without a license....Fraud and misrepresentation is one

> type of tort in which librarians might get involved,...if you are hesitant about disseminating the truth and, with all good intentions, say something misleading in an attempt to make a person happy...As far as negligence is concerned, I don't think librarians could get into any trouble because it would have to be proved that the librarian had a duty and failed to act in a proper manner based on his or her knowledge, experience, and training; and, as a result of that, damage resulted which proximately flowed from the negligence....Constitutional Law will enter into a librarians's deliberations at times because many municipalities, universities, and agencies have contractual relationships with libraries and there can be contractual legal implications.[59]

This may dispel most fears a librarian may have in providing health information. The ethical-professional obligations seem to be the positive ones, to support the constitutional right to know, without fear or intimidation.

PUBLIC LIBRARY TRENDS

How much practical information, applicable to "do-it-yourself" health care and personal problem solving, and how much medico-scientific data and materials can be gathered by general libraries where acquisition policies must be very catholic? Can they afford to buy, is there enough being published and recommended to make library use worth while? Can the educated lay person continue to update his understanding of medical research, technology, economics, and politics by relying on what his public library can offer? Reviewing some pertinent ongoing activities and programs in individual libraries, perhaps one will see trends indicating what progress, if any, has been made to serve general information needs:

The Chicago Public Library, for more than fifty years, has been serving numerous health care agencies. In 1974, about half of the 74

agencies (mostly social services) were devoted to health care, for example, nursing homes, institutions, etc. Thus their Special Extension Services loaned specially prepared educational and recreational materials to selected target groups.[60] Mention is made of staffing for bilingual (Spanish) service and for other minority groups, but not of in-depth collection building or of a concern for policy makers or health consumer activists as potential users.

The same review describes the Detroit Public Library with its services and concerns for the homebound and the elderly. It also has some informal arrangements to provide hospital patients with recreational reading. Here channels have come into existence for cooperation among special institutions and libraries, a link between hospital employees (not the physicians) and public librarians. But the channels do not seem to open up direct access to the wide range of information resources for the acquiring individual. These and similar services probably provide for books to amuse the reader during his hospitalization or institutionalization or perhaps to provide material for "bibliotherapy." They do not define among their goals providing health information to meet individual demand.

The Cleveland Public Library too promotes specialized service to groups with special problems (the blind, patients in hospitals, in institutions, etc.). Additional emphasis is placed on the educational needs of health agency personnel. This contact results in book selection criteria based on outside recommendations to fill some of the special needs described above.

The Toronto Public Library extends its lending into hospitals thus reaching the short term interests of patients during their stay but not necessarily opening up resources for continuous health information gathering for all interested.

The Nassau Library System extends professional advice and book processing to those health-care institutions which have their own, but only minimal, library service. Several more county services describe their "outreach" programs (finding potential new users) and their bookmobile and delivery services mostly to institutions. None seem to emphasize health science collection building in order to provide materials for the health care questions of consumers and consumer groups, and to serve in general and in-depth in the political, decision-making, and planning needs or to promote "scientific literacy." There is no evidence that librarians make heroic efforts to continue their education in this subject field. And the special programs described above were already suffering and anticipating cutbacks in the mid-1970s.[61]

An interesting prototype of information-sharing mechanism across disciplines and professions is described by the librarian-coordinator of the Syracuse gerontology network.[62] This experiment went beyond the usual communication patterns of traditional library service, seeking analogy with the scientific information exchange of "invisible colleges." (Such an informal intelligence network consists of individuals engaged in research or interested in a common field of knowledge who exchange their findings through personal contacts prior to publication or dissemination of the results.) It is suggested that libraries, too, can expand their

reach through imaginative, creative effort and thus become more aware of existing needs and sources than they would be by the traditional passive mode. Libraries can contact and solicit service agencies, educators and government programs, and maintain a flow of primary resource material of practical value and applicability.

The Syracuse network is apparently a referral service for the users to have direct access to those who create and develop new knowledge. However, this too is targeted for a special need in a special subject interest--to find answers for gerontological issues. An interesting concept is discussed by Dosa, that of the "gatekeeper [who] is a relayer of messages among his colleagues as well as between members of his organization and outside information source."[63] The Syracuse HISP (Health Information Sharing Project) tests this role as a library function by using resources beyond libraries including in-house reports and files of local agencies. Its main objective is to facilitate the flow of health information in a community. It emphasizes planning, management, and research information for organizational, agency, and bureaucratic services. Preliminary research showed that traditional cooperation among medical libraries, information and referral services, and management information systems is practically non-existent. Libraries, like the other types of information sources, function independently and unaware of each other.

Specially funded, probably only short term, projects are exemplified by the M.D. Anderson Hospital and Tumor Institute of the University of Texas program for obtaining library service for its patients. Here again, a special group is to be served, meeting special needs of chronic

or terminal patients and their families. The project includes training for librarians to develop understanding (empathy) for the clients of the institute.[64]

Small public libraries' budgets are obviously quite limited to build extensive and expensive, specialized and up-to-date collections. Such materials would be valued by a narrowly limited number of users only, yet could expect use of great intensity and scope. Their resources must be small, nevertheless contain current and scientifically accurate reference books. That this need has been recognized is demonstrated by recurring bibliographies of medical reference tools for the layperson in library journals, often compiled by the library staff or public libraries.[65]

MEDICAL LIBRARIES

One finds somewhat timid attempts to refer inquiring laymen to the specialized, more totally comprehensive, academic, health sciences libraries. Only informal, personal agreements exist; the general rule remains not to invite the "consumer" but rather to discourage him to invade the professional literature collections.

A unique library project in 1978 proposed to change this closed-to-the-public policy and allow lay people easy access to accurate and relevant health-related literature. The project, called the Community Health Information Network (CHIN), links half a dozen public libraries in Massachusetts with the Mount Auburn Hospital Health Sciences Library in Cambridge.[66] Originally financed by NLM (National Library of Medicine),

it was expected to receive continued funding through contributions from all participating institutions. The goals included the establishment of formal cooperation among special and public libraries, training of public librarians in the area of health sciences literature and collection development, shared union lists, and research into existing information needs. This research, however, is restricted to the needs of the health providers of the particular communities in question and does not include the needs of the public at large. The program is trying to establish standards for judging the worth of new health sciences material, print as well as other media.

CHIN demonstrates the timeliness and feasibility of providing health information to a more general public. It also demonstrates, through its limitations, the inherent problems already discussed. These are, for example, the lack of subject knowledge among librarians wishing to undertake such a "gate opening" role, the necessity for special funding, the need to overcome negative attitudes in the medical profession, and last but not least, the self-limiting goals of trying to define within the library who needs such information: the focus then is not the public in general and its activist representatives but perhaps only specific interest groups (for example, La Leche League) and even more typically the already well informed medical and health care professions.

A similar contemporary program in Los Angeles, the CHIPS project (Consumer Health Information Program and Services) seems to demonstrate again that hospital and public library cooperation can channel information

resources to the consumer, but limits this access severely to those who are patients in institutional care and who have educational needs as determined by the health care provider.[67]

Another pilot program in Cleveland, about a year old, is also a cooperative effort, federally funded, between the Cleveland Health Sciences Library at Case Western Reserve University and the Cleveland Area Metropolitan Library System (CAMLS). Its goals are to identify health-related information sources within the community and to produce bibliographies on key health topics. It is designing educational programs for librarians as well, to help them to a better understanding of health topics. These educational programs use members of the medical profession as instructors. Ultimately, the Cleveland program is to design model information services in several public libraries.[68]

Such are the somewhat groping attempts of cooperation between medical and public libraries. Programs like these are not yet generally available, not clearly evaluated, in existence with the help of temporary funding only.

Some librarians are too timid to invite the public in an area they were probably trained to consider as the property of the medical profession alone. Those who serve the profession seldom seek the opportunity to open the doors to the non-initiate as well. Or, if they do, they might face restrictions by the fact that medical libraries are physically separate, often an integral part of an institution administered for the professionals for their teaching or clinical needs. Though policies defining user groups, those who may have access to library material and

services, are rarely explicit, the "typical" medical librarian continues to adhere to loyalties toward the profession only. The "typical" hospital librarian may be serving the patient indirectly through the health care providers.

There is more, much more, medical librarians could do while watching these tentative developments, questioning the expanded role, and feeling limited by the medical profession's almost exclusive demand on the existing health information resources. The problems to be addressed are both political and economic. The needs and some strategies for solution have been demonstrated by individual library programs coming into existence.

The existing, well organized, and relatively well supported national medical library service is greatly limited by its principal mission which is to serve medical research and clinical professional practice and thus only indirectly the general public. It is up to the profession of medical librarians to work toward some change and to offer and adapt existing services and institutions to the much broader information needs of the consumer, of society.

Medical research and resource libraries have the tremendous national network backing them up through the National Library of Medicine's bibliographic databases and its establishment and support of a Regional Medical Library Program. These particular factors, supported by the passage of the Medical Library Assistance Act of 1965, have furthered the leadership role of medical libraries in accessing and disseminating medical literature through on-line bibliographic databases (for example,

MEDLINE - Medical literature on-line) and through formalized and subsidized resource sharing (loans to other libraries) within the Regional Medical Library Program. (The current activities of medical libraries and the above-mentioned programs are summarized briefly in the 1979 volume of Advances in Librarianship.[69])

NATIONAL LIBRARY OF MEDICINE (NLM)

The Library serves as the Nation's chief medical information source. The NLM is authorized to provide medical library services and on-line bibliographic searching capabilities, such as MEDLINE, TOXLINE, etc., to public and private agencies and organizations, institutions, and individuals. It is responsible for the development and management of a Biomedical Communications Network, applying advanced technology to the improvement of biomedical communications, and operates a computer-based toxicology information system for the scientific community, industry, and other Federal agencies. In addition, the Library acquires and makes available for distribution audiovisual instructional material, and develops prototype audiovisual communications programs for the health educational community. Through grants and contracts, the Library administers programs of assistance to the Nation's medical libraries which include support of a Regional Medical Library network, research in the field of medical library science, establishment and improvement of the basic library resources, and supporting biomedical scientific publications of a nonprofit nature.[70]

RECOMMENDATIONS

Some ideas which could be addressed by individuals and by the Medical Library Association are:

1. Evaluate those existing cooperative library services which reach the public community wanting medical information. Examine the impacts on medical resource libraries and on public libraries.
2. Continue efforts to publicize and offer health information through special programs on the community level.
3. Develop the librarians' skills to select and interpret existing information at various levels of comprehension.
4. Seek understanding, cooperation, even support from the medical profession toward the goal of opening medical libraries to the lay person.
5. Design pilot projects, solicit governmental and private funds for implementation.
6. Expand the use of existing databases by searching and identifying especially the up-to-date, scientific, but not necessarily esoteric medical literature for general consumption. For example, code those MEDLINE citations which are particularly useful for non-professionals.

7. Include access to literature which has political, economic, social, and other non-technical bearing on health care issues.
8. Include in the formal training of medical librarians skills to interpret the needs of the non-professional. Share the medical librarian's knowledge in accessing medical literature with librarians serving the general public.
9. Support actively, through the library's resources, existing and potential public health education programs in schools, colleges, and continuing education courses (not merely the educational programs for professionals).
10. Review and index systematically valuable health information in the media, especially in popular magazines and popular book publishing. (A subject index could be selecting data on health topics from existing guides covering broader topics.) Publicize negative findings as well, to eliminate faddist literature.

These are just a few, tentative suggestions, a few of the candles to be lit, in preference to cursing the darkness. Solutions can be manifold. Support might be found from the medical profession itself which sees a more humanistic attitude emerging among its younger generation. Support can also be solicited from governmental and other agencies whose goals are a healthier and politically more alert and active citizenry. Furthermore, support could be found from the marketplace: insurance companies and other health care providing industries who need the

economies, the understanding, and the intelligent and productive utilization of their services. Health care resources are not infinite, even though their recent growth might suggest that. Only knowledge and understanding on a much wider base will help find the solutions our society and its individual members are seeking. There is a long way to go before our quality of life will reach the level which existing science and technology are promising.

FOOTNOTES

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